Older People Living With HIV Issue Call to Action

Glasgow Manifesto calls for care, quality of life and empowerment for aging and older adults living with HIV.

October 27, 2022 By Liz Highleyman

An international coalition of older people with HIV has issued a new manifesto calling for greater focus on the needs of this group. Initiated at the International AIDS Conference this summer in Montreal and released at the HIV Drug Therapy meeting this week in Glasgow, the manifesto is endorsed by more than 100 HIV/AIDS organizations worldwide.

Just over half of people living with HIV in the United States are age 50 and older. Thanks to the growing availability of effective antiretroviral treatment, the number of older people with HIV in lower- and middle-income countries is rising as well. Yet "the HIV response has not evolved with us," according to the manifesto.

In the spirit of The Denver Principles, the first set of demands issued by people with HIV at a lesbian and gay health conference in 1983, the call to action is divided into three sections covering care, quality of life and empowerment. "We all deserve age-friendly and age-affirming information, care, services and support that considers the impact of our HIV status, gender identity, sexual orientation, citizenship, ability, race, ethnicity and place of residence, among other factors," the statement concludes.

Below is the full text of the Glasgow Manifesto, which is available online, including references and a list of supporters, deleted here.

The Glasgow Manifesto
International Coalition of Older People with HIV (iCOPe HIV)
October 2022

PREAMBLE
At AIDS 2022 in Montreal, Canada, we—aging and older adults living with HIV, long-term survivors of HIV/AIDS, and our allies from around the world—gathered in The Silver Zone, the first-ever global village networking zone to hold dedicated space for us. Our 6-year struggle for visibility within the International AIDS Conference is representative of the challenges we face every day to

have our living expertise acknowledged and our needs addressed by our peers living with HIV, our community-based organizations, our healthcare teams, our government officials, and global leaders in the HIV response.

Older people with HIV are NOT collateral damage to be left behind in the pursuit of “ending the HIV epidemic.” We are a silent majority. In 2020, there were an estimated 7.5 million of us (age 50+) around the world. Close to 40% of us who live in high-income settings will be at least 60 years old within the decade, and by 2040, over 9 million of us who live with HIV in sub-Saharan Africa will be over 50. If we speak in unison, we cannot be ignored.

Our bodies, hearts, minds, and pocketbooks reveal scars earned building the modern HIV response. As we age, many of us are living with multiple chronic health conditions, coping with frailty, disability and/or cognitive changes, becoming more socially isolated, and experiencing ageism in addition to HIV stigma and other forms of discrimination. Our independence, quality of life, and longevity are compromised and yet the HIV response has not evolved with us. It is past time for us to assert our rights to health, dignity, and support!

Equitable health outcomes for aging and older people living with HIV will only be possible if we work in collaboration. Those of us with lived experience and living expertise must be at the center of any decision or action taken in response to our self-identified needs. We call on healthcare providers, researchers, community-based HIV organizations, frontline providers of ageing-related services, and policy- and decision-makers to work in partnership with us to fund and implement the following calls to action.

CALLS TO ACTION

We, aging and older adults living with HIV, call for:

CARE

1. Tailored care. Work with us to develop new models of care for ageing and older people living with HIV that account for the health and social complexity we experience. At a minimum, this model should be multidisciplinary, integrated, proactive and preventive, and organized around our priorities. We need more time with our care providers.

2. Wholistic care. We demand access to services and technologies that can help prevent and reduce the disabling impact of chronic illness, frailty, and cognitive changes (e.g., rehabilitation services, vision and hearing care, dentistry, mental health services, mobility/hearing/vision aids, cognitive supports, personal care, in-home support for activities of daily living, etc.) regardless of our ability to pay.

3. Access to care. We insist on low-barrier care and services, whether delivered in the clinic, community, or virtually. We have a right to reasonable accommodation.

4. Safe aging care. We demand that individuals and organizations providing care and services to older adults be knowledgeable about HIV, the lived experiences of people living long-term with

HIV, our distinct support needs as aging persons living with HIV, and the impact of HIV stigma. Individuals and organizations providing HIV care and services should be similarly conscious and renounce ageism. Service providers require education on our clinical and social needs to support us better. We have the right to respectful, informed ageing care without discrimination.

QUALITY OF LIFE

5. Dignity. We expect that our sexual health is considered a vital part of our overall health.

6. Respect for our living expertise. We are self-aware, take responsibility for our well-being and demonstrate great resilience, having developed effective strategies for maintaining wellness in the face of adversity. We want care providers and researchers to ask us about our quality of life, and to prioritize what we deem most important.

7. Age-affirming community responses. We urge HIV organizations to address ageism within; work with us to develop responses that are relevant to our needs, including companionship and peer support; and foster intergenerational understanding and community-building.

8. Healthy living conditions. We demand that our right to an adequate standard of living and social protection, as guaranteed by the United Nations Convention on the Rights of Persons with Disabilities (Article 28) be realized. We implore policy makers to respond to the unmet needs of ageing and older adults in their jurisdiction who struggle to afford adequate housing, food and/or other resources for health because of HIV-related disability.

EMPOWERMENT

9. Targeted research and education. We expect that aging and older adults are represented in all HIV research and that people living with HIV are included in ageing research, so we are clear on what the findings mean for our well-being. We insist on more research focused on HIV, ageing and older adults that responds to our community-identified priorities. We demand access to the most up-to-date information on aging with HIV to inform our decision-making, self-care activities to prevent illness and maintain health, and planning for the future.

10. Meaningful involvement. We demand that aging and older people be included in decision-making about the HIV response, including priority- and target-setting, funding allocation, and messaging about the impact of HIV on ageing and older adults.

We—aging and older people living with HIV—are not a homogenous group between nor within countries around the globe, so we expect these CALLS TO ACTION to be implemented in ways that are equitable and account for intersectionality. We all deserve age-friendly and age-affirming information, care, services, and support that considers the impact of our HIV status, gender identity, sexual orientation, citizenship, ability, race, ethnicity, and place of residence, among other factors.

It is with great urgency that we, the International Coalition of Older People with HIV (iCOPe HIV), implore all stakeholders to work with us to implement these CALLS TO ACTION without further

delay.

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